SOCIAL SERVICES FOR INDIVIDUALS WITH DEMENTIA AND THEIR FAMILY CARERS AS PERCEIVED BY STUDENTS AND SOCIAL WORKERS

USŁUGI SPOŁECZNE DLA OSÓB Z DEMENCJĄ I ICH OPIEKUNÓW RODZINNYCH W PERCEPCJI STUDENTÓW I PRACOWNIKÓW SOCJALNYCH

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ABSTRACT

The family's potential to provide care is diminishing due to the ongoing processes of modernisation and nuclearisation of the family, as well as population migration. The diminishing role of horizontal ties and the verticalisation of the family network are becoming aspects influencing the increase in the number of people requiring care, while the number of potential carers is decreasing. The decline in the family»s caring potential will intensify the demand for social services, fostered primarily within the home, on account of the growing process of deinstitutionalisation. This paper presents the results of a survey conducted in the Podkarpackie Voivodeship in 2025 among social workers and full-time first- and second-cycle social work students. Individual in-depth interviews (IDI) were used during the research . The purpose of the study was to provide answers to questions about the implementation of social services aimed at individuals with dementia as well as family carers. The research aimed to address questions regarding the preparation of social work students and social workers for working with individuals with dementia and their family carers as well as the implemented and expected social services that have been implemented, along with the factors facilitating or hindering their delivery.

Key words: disability, neurodegenerative disease, social services, family carer.

ABSTRAKT

*Potencjał opiekuńczy rodziny zmniejsza się w związku z postępującymi procesami jej modernizacji i nuklearyzacji oraz migracji ludności. Zmniejszenie roli więzi horyzontalnych i wertykalizacja sieci rodzinnej stają się aspektami wpływającymi na wzrost liczby osób wymagających opieki, przy jednoczesnym spadku liczby potencjalnych opiekunów. Zmniejszanie się potencjału opiekuńczego rodziny będzie zwiększało zapotrzebowanie na usługi społeczne, rozwijane przede wszystkim w miejscu zamieszkania, ze względu na postępujący proces deinstytucjoanlizacji. Artykuł przedstawia wyniki badań zrealizowanych w województwie podkarpackim w 2025 roku wśród pracowników socjalnych i studentów studiów stacjonarnych pierwszego i drugiego stopnia kierunku praca socjalna. Podczas badań zastosowano wywiady indywidualne pogłębione (*in-depth interview, IDI*). Celem eksploracji było przedstawienie odpowiedzi na pytania dotyczące realizacji usług społecznych skierowanych do osób z demencją i do opiekunów rodzinnych. Poszukiwano odpowiedzi na pytania badawcze dotyczące przygotowania studentów kierunku praca socjalna i pracowników socjalnych do pracy z osobami z demencją i opiekunami rodzinnymi, ponadto realizowanych i oczekiwanych usług społecznych, a także czynników ułatwiających i utrudniających ich wykonywanie.*

Słowa kluczowe: *niepełnosprawność, choroba neurodegeneracyjna, usługi społeczne, opiekun rodzinny*

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INTRODUCTION

The family's potential to provide care is diminishing due to the ongoing processes of modernization and nuclearization of the family, as well as population migration. .The verticalisation of the family network and the diminishing role of horizontal ties are elements that influence the rise in the number of people who require care, while the number of potential carers is decreasing. The decline in the family»s caring capacity will therefore increase the demand for, among other things, social services[1] fostered within the home (Szluz, 2021, p. 103).

The observable ageing of the population is leading to a rise in the number of elderly individuals, resulting in an increase in the number of people experiencing neurodegenerative diseases[2] (such as Alzheimer's, Parkinson's, or Huntington's disease). According to the Commission on Chronic Illness in the United States, chronic illnesses are "any disorder or deviation from the norm that has one or more of the following characteristics: is permanent, leaves disability, is caused by irreversible pathological changes, requires special rehabilitation procedures, or by all expectations will require a long period of supervision, observation or care" (Shontz, 1972, p. 300). The symptoms and progression of the disease are challenging for patients, as well as a burden for carers. Family carers face numerous challenges, including physical, mental, social, and financial difficulties (de Walden-Gałuszko, 2004, pp. 164-166; Szluz, 2021, pp. 103-118). Caring for a sick person is physically and mentally exhausting, as well asan economic burden, so it is essential to develop local deinstitutionalisation plans that take into account the needs of family carers and sick persons. They will provide them with access to care, assistance and social support, and in the context of the deinstitutionalisation process, will be aimed at developing a variety of social services at the local community level, which are expected to reduce the need to refer the person to institutions offering care in the form of 24-hour stays.

The development of social services is occurring primarily in daytime institutional forms; however, they can also be provided on a 24-hour basis. The first type can include: (1) support centres, as referred to in the Law on Social Assistance (Journal of Laws 2024, item 1283, Article 51), providing support in the day system, including: day centres, senior+ homes and senior+ clubs; (2) community self-help homes and self-help clubs; additionally, (3) medical day care homes; (4) care farms; (5) entities that support the socio-professional reintegration of individuals with disabilities (social cooperatives, occupational therapy workshops); (6) social welfare homes — regarding the provision of short-term stays in the form of day care, care services and specialised care services for non-residents, on the basis of Article 55 (3) of the Social Assistance Act (Journal of Laws 2024, item 1283), as well as conducting activities in the form of a support centre, training and assisted living houses, and providing respite care. On the other hand, the second type—entities that provide services around the clock—may include: (1) services in support centres, as referred to in the Law on Social Assistance, provided that the number

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[1] Social services are 'carried out by a municipality to address the needs of the self-government community, and provided in a non-material form directly to individuals, families, social groups, groups of residents with specific needs, or the general population,' (Journal of Laws 2019, item. 1818, article 2).

[2] Neurodegenerative diseases are not exclusive to older individuals.

of 24-hour places in these centres does not exceed 30; (2) respite care—the creation of short-term placements to provide temporary relief during the absence or rest period of the primary carer—offered in the form of 24-hour or daytime support for carers; (3) services in the form of assisted living housing; (4) services in a family care home, as referred to in the Social Assistance Act (accommodating between 3 and 8 individuals); (5) residential and care centres, as one form of support centre; (6) community self-help homes offering 24-hour accommodation; (7) social welfare homes implementing short-term 24-hour stays; and (8) social welfare homes as the final form of support when adequate assistance and a sufficient range of services cannot be provided at the individual»s place of residence (Ministry of Family, Labour and Social Policy, 2025, pp. 17-19). Undertaking social work focuses on strengthening the ability of individuals with illnesses to function within their families and society while fostering conditions that support family carers and relatives in fulfilling their social roles. Among the social worker»s areas of support, the following should be noted: strengthening the ability of sick persons to meet basic needs in their residential environment; increasing access to rehabilitation; reducing the impact of a family member's illness on children and adolescents; enabling the sick and their carers to engage in various forms of social life; supporting the participation of sick persons and their families in support and self-help groups; encouraging local community involvement in assisting families; increasing awareness of the rights and entitlements of sick persons and their families; and providing social support and services, including social work (Regulska, 2013, pp. 240-241).

The findings of a survey (Wielgos-Strucik, Kotarski, Bozacka 2017, pp. 55-77) conducted among students majoring in social work are cause for concern (N=112, survey technique) [Podkarpackie Voivodeship]. Students had a low level of knowledge about Alzheimer»s disease and the challenges faced by patients and their families. Among second-cycle students, 20% responded affirmatively to the question of whether Alzheimer»s is a natural consequence of ageing, while the percentage among third-year students was as high as 25.3%. According to 49.1% of respondents, the cause of memory problems was dementia (50%), as well as age (49.1%). According to 49.1% of respondents, the cause of memory problems was attributed to dementia (50%) and ageing (49.1%). The predominant response was that Alzheimer»s disease is a condition affecting the human brain (97.3%), while a small percentage of the hundreds of students (2.7%) mistakenly identified it as a disease of the kidney. Students perceived the diagnosis of Alzheimer»s disease as being handled by specialists such as neurologists (68.8%), psychiatrists (29.5%), geriatricians (21.4%), and general practitioners (13.4%). Regarding patient care, students believed it is most often provided by family members (61.6%), followed by nursing homes (17.9%) and hospitals (5.4%), while 15.2% of respondents had no knowledge on the subject. Half of the respondents rated their level of knowledge on a five-point scale as '2' or lower. The average knowledge level among students was 2.43. The students expressed interest in volunteering with an NGO and expanding their knowledge of dementia. Several years later, another survey was conducted in the Podkarpackie Voivodeship, this time including not only students but also social workers.

ASSUMPTIONS OF THE RESEARCH PROJECT

The main objective of the conducted research was to seek answers to questions regarding social services for individuals with dementia and their family carers. The research aimed to identify responses to the following questions: How are social work students and social workers prepared to work with individuals with dementia and family carers? What social services are currently provided, and what are the expectations for future services? What factors facilitate or hinder the implementation of social services in this field of activity? The research was conducted from January to March 2025 in the Podkarpackie region, using thein-depth interview (IDI) technique. To protect personal data, the names of localities and other personal identifiers have been removed (anonymisation was done).

The study included social work students and professionals practicing as social workers. (in the Podkarpackie Voivodeship region).[3] It was conducted among full-time, social work students (N=15), as well as first (8) and second-cycle students (7).[4] The respondents were predominantly female (12). Respondents were between the ages of 18 and 24. Among the surveyed social workers (N=15), women were the majority (13 individuals), reflecting the observed feminisation of the profession. Respondents were individuals between the ages of 26 and 64. They more often held a master»s degree (10) than a bachelor»s degree (1). Three had completed post-secondary education, and one had obtained a doctoral degree. Among the respondents, 10 worked in social welfare centres, evenly split between rural and urban municipalities (5 in each). Five individuals were employed at a social service centre operating in a rural municipality. The respondents had been in their positions for 1 to 10 years (7 individuals), 11 to 20 years (5 individuals), and 21 to 30 years (3 individuals).

In summary, based on the adopted criteria for purposive selection, the respondents included first-cycle social work students (8) and second-cycle students (7), aged 18 to 24. The respondents were social workers between the ages of 26 and 64, with most having completed a second degree in higher education. A greater number of respondents worked in rural municipalities, with those having less than 10 years of experience forming the majority. Due to the observed feminisation of the profession, the survey included 25 women and only 5 men.

PRESENTATION OF RESEARCH FINDINGS

Students that majored in social work participated in classes (in the first-cycle program: social gerontology; in the second-cycle program: sociological aspects of old age and ageing). They also conducted visits to social institutions and completed student internships. However, they rated their substantive preparation for working with individuals affected by dementia as 'very poor.' Only three had practical experience, which they had acquired by assisting their parents in caring for a family member with dementia. A respondent emphasised the importance of patient care within their home, identifying key areas of support and entities responsible for assisting both the family and the individual affected by dementia.

> Caring for a person with dementia in their own home should be based on adapting the environment to their needs, such as eliminating hazardous objects and ensuring a well-lit room layout. Establishing a consistent daily routine is essential, as it can help reduce disorientation and enhance the patient's sense of security. Additionally, support from external institutions, (...) community carers, social workers, and volun-

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[3] The study was subsidised by the University of Rzeszów.

[4] Individuals studying Sociological Sciences at the University of Rzeszów.

> teers can significantly alleviate the family's burden and make the patient's life more comfortable. (W25, K22/lic.)[5]

Social workers rated their substantive preparation for working with individuals with dementia as 'poor' or stated, 'I have had no preparation' (11 respondents), while only four rated it as 'good.' Few had acquired knowledge during their studies, study visits, courses, webinars, or seminars. Social workers were more likely to gain knowledge through professional experience—building expertise through direct contact with affected residents or learning from other social workers

> Communicating with an Alzheimer's patient can be very difficult (...) However, carers must possess extensive knowledge of the progression of the disease, an understanding of the patient's atypical behaviour, and proficiency in specific techniques for communicating with individuals who have impaired memory function and a distorted perception of reality. (...) My preparation is poor. (W14, WK37/1) [6]
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> There were some issues in our studies. We even had a subject taught by a geriatrician specifically focused on Alzheimer's disease. Let us say it was only a single meeting where this person was able to explain it to us and provided an illustration of what it looks like. Besides, I believe that in addition to studies, we also just rely on our own experience, and the experience of senior colleagues at work. (...)' (W1,MK26/2)
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> Well actually, this preparation in studies, (...) study visits to such day care centres, aimed specifically at those people with issues, with dementia, with memory. (...) Here, we also had access to webinars, courses, and informational resources provided to our centre and to us.' (W2, MK29/3)

The social workers surveyed also indicated a lack of knowledge and skills in working with family carers and the families of an individual with dementia. The statements of the respondents depict an image of a 'transparent,' 'absent' family carer and an 'overlooked' family of the person affected by the disease. "If there was already something being addressed, it was only the topic of this sick person, rather than focusing on the carer, the individual's family" (W1, MK26/2).

However, they pointed out that the heavy burden of family care responsibilities can lead to burnout. Carer syndrome is a state of physical and mental exhaustion that occurs when providing care for a person experiencing a chronic illness, a person with a disability.

> Carers must also have a sense of their own life, that they simply are not condemned to solely taking care of this individual, that they are not condemned to only the company of this individual, but that they can also just... they can do their own things somewhere, they can go out, have their own friends (...) to be a little bit (...) independent, because the disease places significant limitations on the carer, and (...) so that the care is shared, (...) so that it doesn't all fall on one person, because they may burn out over time, well, with this care. (W1, MK26/2)
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> In a home setting, when possible, it is important that each family member contributes to the care of the patient. For one person, this task may prove too overwhelming.

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[5] Student designations: W number – interview number, lic. – first-cycle, mgr – second-cycle student.

[6] Social worker designations: W number – interview number, W/M – place of work: rural/urban, K/M –gender: female/male, number - age of the respondent/ years working as a social worker.

> If you decide to care for the sick person at home, it's a good idea to have a discussion with all family members, dividing up responsibilities and distributing tasks, such as turning off the gas, locking the door, etc. (W7, WM27/2)

They also acknowledged the importance of sharing care responsibilities and involving other family members in the care of the sick person. However, if the family carer lacks a care convoy,[7] it is essential to develop social services tailored to the needs of the sick person and the family carer, resulting in the delegation of some of the tasks, enabling the carer to remain professionally active without having to give up their role as a worker.

Social work students had no knowledge of coordinating activities aimed at residents. In turn, social workers employed at social welfare centres observed that activities for the patient and their family were not properly coordinated. They advocated for the formation of teams that would collaborate under the guidance of a coordinator trained to work with individuals with dementia:

> Activities, I think to myself of all those interdisciplinary services that would have access to such a person, which would have the knowledge on how to assist this individual, since, one knows this...the other knows that, as if it were also compatible together, then it would probably be easier for this person to get such support. (W4, MK50/23)

Few perceived the role of coordinator as solely belonging to the head of the social service centre. Employees of the social service centre expressed a different perspective, highlighting the possibility of utilising the community interview and social contract in this area, as well as individual social service plans developed by coordinators: 'Support for family members, depending on the support received, is coordinated through individual social service plans, community interview or social contract' (W11, WK36/10).

The aforementioned plans are developed and synchronised by coordinators of individual social service plans and employed at social service centres. These services are tailored to the needs of residents (so-called 'tailor-made' services). This approach aligns with the ongoing process of deinstitutionalisation, and therefore allowing residents to remain within their home:

> Care services provided within the home should include information about nursing homes, day care options, here actually, well, social work, both counselling, and psychological, here I am saying that conversations and guidance are particularly important for individuals in need of such services, that families are not simply separated, allowing the individual to stay within their home, and always support the rest of the family members. (W5, MK42/8)

Respondents listed the social services (realised and desired) that are, or should be, implemented by staff at social service centres, social care centres, or other entities. These services are intended to support individuals with the disease, as well as family carers and the families of those with dementia (see Table 1 and Table 2):

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[7] Care convoys are an evolving collection of individuals who do no necessarily have a close personal relationship with the care recipient or with each other and provide care, including assistance with daily activities, emotional support, professional medical care, as well as other activities (Kemp, Ball, Perkins, 2013, s. 15–29).

Table 1

Social services for an individual with dementia, family carer, family of the individual with dementia — according to social workers

Services for individuals with dementia	Services for the family carer, family of the afflicted individual
‘psychiatric care, psychological care, community nurse’	‘psychological counselling, assistance at the psychological-educational counselling centre’
‘care services, including specialised care services’	‘specialist counselling, nursing care/ rehabilitation, dietetics’
‘neighbourhood services’	‘social counselling’
‘disabled person assistance service, elderly people assistance service’	‘legal counselling, including during the incapacitation of a sick person’
‘telecare, the so-called “senior wristband” in the home of the afflicted individual	Should the afflicted individual possess a certificate for self-sufficiency, assistance in the form of a care allowance after resigning from employment to care for the sick person’
‘assistance of a social worker in organising rehabilitation and health services’	‘respite care’
‘assistance in obtaining rehabilitation equipment, among others, equipment rental shops for individuals with disabilities’	‘the social worker can offer training and practical activities and the exchange of experiences for live-in carers, increasing their competence in caring for people with dementia’
‘assistance in obtaining rehabilitation sessions, funding for the elimination of architectural barriers, e.g. from the State Fund for the Rehabilitation of the Disabled (PFRON)’	‘the social worker develops a support plan, assists with the completion of documents, e.g. for the Social Insurance Company (ZUS)
‘financial assistance, including assistance in the form of: permanent benefit, periodical benefit purpose-specific benefit, cash allowance for the purchase of food or meals’	‘assistance in obtaining information to navigate the various support systems, the use of which is essential to provide quality care and relieve the burden placed on live-in carers, e.g. Alzheimer’s associations and support groups’
‘assistance in kind, including, inter alia, transporting meals to the pace of residence – pursuant to provisions of the Social Assistance Act’	‘support groups, including via the Internet’
‘services in support centres referred to in the Social Welfare Act providing daytime support (day care homes; senior+ homes and senior+ clubs), short-term support services provided in the form of round-the-clock stays in social welfare homes, in addition to family support homes and social welfare homes”.	‘self-help groups’

Table 1
Social services for an individual with dementia, family carer, family of the individual with dementia — according to social workers (continued)

Services for individuals with dementia	Services for the family carer, family of the afflicted individual
'enabling the use of supported housing with a basket of services'	'services provided by NGOs'
'assistance in arranging a place in a care home, assisted living facility or hospice'	
'assistance in arranging a place in diurnal psychogeriatric wards, 24-hour psychogeriatric wards'	
'referring individuals with dementia to the District Disability Assessment Board to establish the degree of disability'	
'transportation service (*door to door*)"	
'monitoring of the social work provided'	

Source: own elaboration

Table 2
Social services for an individual with dementia, family carer, family of an afflicted individual —according to social work students

Services for individuals with dementia	Services for the family carer, family of the afflicted individual
'care services'	'counselling, assistance from a psychologist, lawyer"
'nursing assistance, assistance of a medical carer'	'support group'
'occupational therapy'	'respite care service'
'rehablilitaion	'care allowance'
'referral to a social welfare home or support centre'	'training for carers'
'financial assistance, including assistance in the form of an allowance'	
'the social worker may coordinate "emergency assistance" in the form of subsidies for the purchase of medication, hygiene products, or equipment to assist with day-to-day living'	

Source: own elaboration

Volunteers, who can 'accompany the afflicted individual on a daily basis,' are also included in the spectrum of activities for residents. They can provide:

> Help with care, help, (...) with getting to centres, help even, like, with toileting, well because many times these are elderly people who vary in age, with different conditions, co-morbidities, I think help in that sense, help with shopping, (...) going out for a walk.' (W3/MM45/23)

> The volunteer can engage in the following activities: conversing with the individual in need of support, helping/accompanying them on walks, helping with shopping and preparing meals together, walking the dog, helping to keep the house in order and helping to contact social welfare homes (OPS) or social service centre (CUS) social workers. (W11, WK36/10)

The surveyed social workers highlighted a shortage of volunteers, particularly evident in rural areas. At the same time, students expressed motivation to engage in volunteer work, which could enhance their knowledge and skills in preparation for a career in social work.

Respondents also recognised factors that hinder the delivery of social services. Social workers noted: 'a lack of knowledge and training in social work with individuals experiencing dementia and their families, a lack of training,' 'reduced direct contact with residents during the coronavirus pandemic, an increase in telephone communication — which made it difficult to work directly with residents,' 'an expanding workload and directing social worker activities towards migrants from Ukraine,' 'long wait times for placement in a social care home' and 'a shortage of places and support centres close to their place of residence.' The surveyed students, in turn, mentioned: 'delayed dementia diagnosis', a shortage of — 'training for carers,' 'family awareness of support options,' 'public awareness of the disease, which hinders the implementation of effective support programmes,' 'adequate number of facilities and specialists', 'limited financial resources for long-term care,' 'adequate financial support for the patient,' 'underdeveloped respite care,' 'cooperation between the family carer, family members of the sick person and the social worker', and 'coordination of activities.' Respondents, both social workers and students, unanimously emphasised that visible are: overloading social workers with duties and bureaucracy, for example, focusing too much on procedures rather than achieving goals and delivering social services, which leads to negative consequences, i.e. foot-dragging, high administrative costs, and decreased staff satisfaction.

Among the factors facilitating the delivery of social services, the social workers interviewed mentioned an increase in: 'increased training for social workers on working with the individual with dementia and the family carer,' 'volunteer support,' 'expanded psychological services, psychiatric care, including community-based services', 'expanded occupational therapy services,' 'expanding the activities of General Practitioners in informing the family carer about the specifics of dementia.' In turn, social work students found it necessary to: 'provide better access to training for carers', they called for 'increased access to specialised services, e.g. assistants for the elderly, and telecare,' 'extended assistance of a nurse/health care provider, psychologist,' 'creating more diurnal support centres, including round-the-clock facilities,' 'adapting the environment to needs, e.g. signage on doors and walls to make it easier for such people to move around and help them organise their day-to-day living,' and 'stimulating memory and maintaining physical activity to prevent the rapid progression of the disease.. Both social workers and students emphasised the need to increase the 'number of support groups,' as well as their creation — especially in rural communities.

SUMMARY

Relieving the burden and ensuring proper coordination of support given to family carers are essential prerequisites for sustaining long-term care by family members within the home for individuals with dementia (familisation of care). The research indicates that coordinators of individual social service plans should collaborate with day care centres and assist family carers in enhancing their competences—for example, through training programs and experience-sharing in support groups or self-help groups. There is a growing need for increased informational support to alleviate the strain on family carers and enable them to provide high-quality care. Respondents identified several factors that facilitate the role of family carers, including: assistance from social workers in addressing various issues, providing access to rehabilitation equipment, expanding access to different types of counselling, obtaining — care services within the home, as well as neighbourhood services, assistant support for individuals with disabilities or the elderly, respite care, volunteer support, telecare, and meal delivery. Social work itself was also highlighted as a social service.

An important element of the deinstitutionalisation process is the role of the professionals providing involved in the provision of social services. It is essential to continuously enhance the qualifications of individuals delivering social services in the community as well as in round-the-clock care institutions, or those providing them in a mixed system , i.e. — partly in the community and partly in an institution, as well as improving the quality and working conditions of their roles. In order to alleviate the workload of social workers, the implementation of e-services is crucial, as well as the incorporation of new technologies to enhance service delivery. Volunteer activities form an integral part of social service delivery; therefore, promoting volunteering is encouraged.

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